

PATIENTS ON ANTIRETROVIRAL THERAPY WHO WERE LOST TO FOLLOW-UP AT A TERTIARY CARE HOSPITAL, PUNE, INDIA.Dileep B. Kadam¹, Sonali P. Salvi², Suryakan Mane³**HOW TO CITE THIS ARTICLE:**

Dileep B. Kadam, Sonali P. Salvi, Suryakan Mane. "Patients On Antiretroviral Therapy Who Were Lost To Follow-Up At A Tertiary Care Hospital, Pune, India.". Journal of Evolution of Medical and Dental Sciences 2014; Vol. 3, Issue 41, September 04; Page: 10297-10305, DOI: 10.14260/jemds/2014/3337

ABSTRACT: Importance: With increasing number of persons living with Human Immunodeficiency Virus (HIV) in major cities there is a need to have a comprehensive strategy to reduce the number of drop outs from the anti-retroviral (ART) therapy. This can be done effectively only when we study the reasons why patients are lost to follow up. This study has brought to light novel causes of non-adherence to ART, like migration, discordance and resort to alternative therapies. **DESIGN:** This is a qualitative study conducted at ART Center, Byramjee Jeejeebhoy Medical College (BJMC) and Sassoon General Hospital (SGH), Pune, a tertiary referral center in India. We included all those patients who were initiated antiretroviral therapy and lost to follow-up (LFU) any time during the entire month after three months during which the appointment was scheduled. All these patients were interviewed during restart of ART, in ART center, BJMC and SGH. **MAIN OUTCOMES AND MEASURES:** All socio-demographic and clinical factors associated with antiretroviral therapy adherence. **RESULTS:** Out of a total 51 patients lost to follow-up, patients above thirty five years of age and male sex were associated with a higher chance of being lost to LFU. Illiteracy rate was high in age group above 35 years (64.1%) and in females. Male drivers were lost to follow-up at a greater extent [14(24.75%)]. Out of 24(47.06%) married patients, 12(50%) male patients were sero-discordant. The chance of defaulting from therapy was high in the first three months and one year later from the initiation of therapy. Migration led to drop out of 13(25.49%) patients. Other important factors leading to loss to follow up were: death in family, side effects of drugs and family disturbance. Alcoholism was the cause in 23(45.10%) male patients. **CONCLUSION AND RELEVANCE:** Migration, illiteracy, alcoholism, discordant couples, death in family, low socio-economic status, resorting to alternative therapies were the prominent factors which directly influenced and aggravated the problem of non-adherence. Targeting these variables will cause definite reduction in lost to follow-up cases.

KEYWORDS: Antiretroviral Therapy, Lost to Follow-up, Adherence.

INTRODUCTION: The finest outcome of antiretroviral therapy can be achieved only with unabridged compliance. In Maharashtra state of India, there are 58 ART centers. ART center B.J. medical college and Sassoon general hospital, Pune was established in 2005. Since then more than 27,000 patients have been registered in HIV care and more than 14,000 patients are presently benefitting from ART. Far fewer people are progressing to AIDS, and the age-adjusted death rate from HIV/AIDS has declined conspicuously. Adherence to ART has emerged as the major determinant in this success.

Non-adherence and incomplete adherence culminates in virological failure, which diminishes the potential for long-term clinical success. Drug-resistant strains of HIV selected through ongoing replication in the presence of ART also can be transmitted to uninfected or drug-naive patients, leaving them with fewer treatment options, ultimately increasing the mortality.¹ Adherence is not the only determinant of ART failure or success. Other factors include genetic differences in drug

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metabolism, severe baseline immune suppression, prior drug resistance, and concurrent opportunistic infections. Adherence to ART, however, is one of few potentially alterable factors determining outcomes for patients with HIV.

This article throws light on various factors having impact on antiretroviral adherence, with a focus on practical strategies for assessing and improving adherence.

OBJECTIVES: To understand the reasons why patients defaulted from antiretroviral treatment (ART) program so as to help design interventions that improve treatment retention and ultimately, patient outcomes.

MATERIALS AND METHODS: This is a retrospective study conducted at ART Centre B.J. Medical College and Sassoon General Hospital Pune, between January 2012 and September 2012. The study was conducted with permission from the Ethical Committee, BJMC, Pune.

INCLUSION CRITERIA: Patients lost to follow up and who restarted ART at our Center.

DEFINITION OF LFU: LFU has been divided into Pre ART and On ART LFU.

PRE –ART LFU: As per the definition of Pre-ART LFU, all those patients under Pre ART care who have been termed as LFU and whose last visit was before more than one year.

ON ART LFU: A patient will be termed as LFU only if he/she does not turn up any time during the entire month after three months during which the appointment was scheduled.

This study is qualitative and focuses on socio-economic status, reason for LFU and why they returned to re-enter in ART program. We attempt to bring to light reasons behind getting lost to follow-up.

DATA COLLECTION PROCEDURE: All LFU patients interviewed during restart the ART, in ART center BJMC Pune.

DEFINITION KEYS AND TERMS:

- LFU: lost to follow up
- ART: Anti-Retroviral Therapy
- BJMC: Byramjee Jeejeebhoy Medical College
- SGH: Sassoon General Hospitals
- Pvt.: Private
- OI: Opportunistic infection
- ORW: Out-reach worker

RESULTS: Out of a total 51 study patients, 11 patients were illiterate. Patients educated to a primary level constituted the maximum number of LFU [21(41.18%)], whereas only 5(9.80%) patients were educated beyond secondary school & college, all being male. Illiteracy rate was high in age group

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above 35 years and in females as compared to males. None of the females was educated above primary level.

Maximum number of patients were driver by occupation [14(27.45%)] with a male predominance. Patients from labour class were 13(25.49%), out of which 8(15.69%) were male and 5(9.80%) were female. Only 3(5.88%) patients had income above Rs.10, 000/per month. 22(43.14%) patient's had income between Rs.2001-5000 out of which 15(29.41%) were male and 7(13.73%) were female. The rest had income below Rs.2000/month. Maximum females [8(15.69%)] had income below 2000. The maximum number of earning people were above 35 years of age. Most of the patients belonged to income group of Rs.2, 001-5,000/per month. 19 (37.25%) patients were from low income group i.e. below Rs.2000/per month.

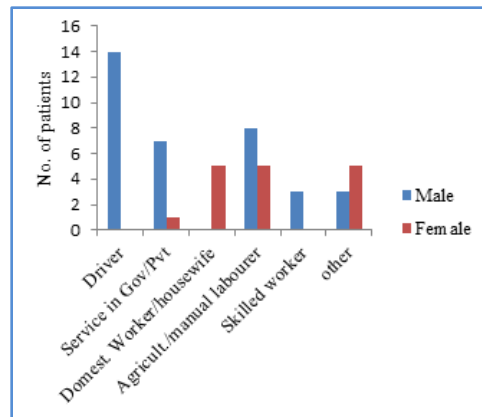


Figure 1: Occupation of LFU cases

Out of 51 patients, 24(47.06%) patients were married (19 male and 5 females), 7(13.73%) males and 7(13.73%) females were widowed, 7(13.73%) patients were single (unmarried) and 6 patients were separated/ divorced. Most of the widowed patients were above 35 years age group.

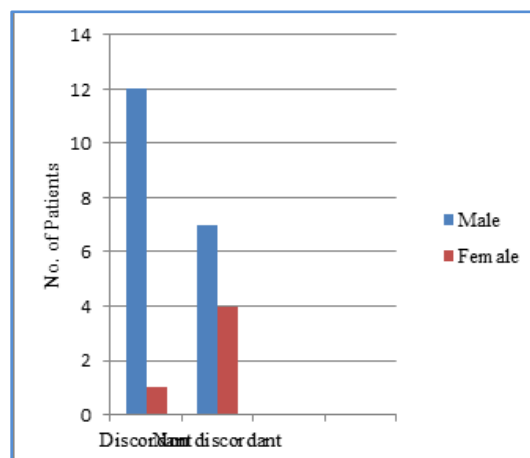


Figure 2: Marital status of spouse and LFU

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Out of 24(47.06%) married patients, 12(50%) male patients were discordant and 1(4%) female was discordant.

Remaining 11(46%) patients were non-discordant. Maximum numbers of patients (26) were living within 20 km distance from ART Centre. Only 13(25.49%) patients were living beyond 100 km from ART Centre.

Migration was the cause of LFU in 13(25.49%). 8(15.69%). Death of a family member was the cause for LFU in 8 cases and 6(11.76%) patients were LFU because of medication related side effects. Family disturbances led to defaulting in 5 (9.80%) and in another 5(9.80%) due to other treatment like alternative medicine. Only male patients resorted to alternative medicine. Psychiatric problems were noted in three cases. Migration was the commonest reason for LFU 13(25.69%) patients and maximum numbers of migrants were above 35 years of age.

Patients who restarted ART after having opportunistic infection were 10(19.61%). Generalized weakness, oral infection, Diarrhea and indoor (hospitalized) patients were observed in 17(33.33%), 1(1.96%), 2(3.92%) and 1(1.96%) respectively. Remaining 20(39.22%) patients were asymptomatic. A significant number of patients were alcoholic and all were male and 18(35.29%) patients were above 35 years of age. Patients who were LFU within 0-1 month were 9(17.65%), within 1-3 months were 14(27.45%), within 4-6 months were 8(15.69%), within 7-12 months were 6(11.76%) and 14(27.45%) patients were LFU after more than one year from initiation of ART.

Patients restarted ART because they returned back to home (10), had weakness (7) or had some opportunistic infection (5). Only 4(7.84%) patients restarted ART in response to phone calls by health care worker and 3 (5.88%) upon doctor's advice. Two patients restarted ART after home visit by Out-reach worker.

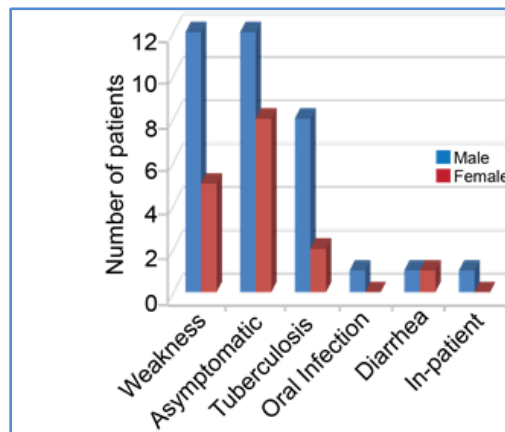


Figure 3: Condition of patient during ART Restart

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	Age				Gender	
	0-14 yrs.	15-25 yrs	26-35 yrs	Above 35	Male	Female
Education						
Illiterate	0	02 _(3.92)	02 _(3.92)	07 _(13.73)	05 _(9.80)	06 _(11.76)
Primary	2 _(3.92)	01 _(1.96)	09 _(17.65)	09 _(17.65)	11 _(21.56)	10 _(19.61)
Secondary School	0	00 ₍₀₎	01 _(1.96)	12 _(23.53)	13 _(25.49)	00 _(0.00)
College and above	0	00 ₍₀₎	01 _(1.96)	05 _(9.80)	06 _(11.76)	00 _(0.00)
Total	2 _(3.92)	3 _(5.88)	13 _(25.49)	33 _(64.71)	35 _(68.62)	16 _(31.37)
Income	0-2000	01 _(1.96)	01 _(1.96)	05 _(9.80)	12 _(23.53)	11 _(21.57)
	2001-5000	01 _(1.96)	02 _(3.92)	05 _(9.80)	14 _(27.45)	15 _(29.41)
	5001-10000	00 ₍₀₎	00 ₍₀₎	02 _(3.92)	05 _(9.80)	06 _(11.76)
	Above 10000	00 ₍₀₎	00 ₍₀₎	01 _(1.96)	02 _(3.92)	03 _(5.88)
	Total	02 _(3.92)	03 _(5.88)	13 _(25.49)	33 _(64.71)	35 _(68.63)
Family status	Single	02 _(3.92)	01 _(1.96)	01 _(1.96)	03 _(5.88)	05 _(9.80)
	Married	00 ₍₀₎	01 _(1.96)	05 _(9.80)	18 _(35.29)	19 _(37.25)
	Separated/divorce	00 ₍₀₎	01 _(1.96)	03 _(5.88)	02 _(3.92)	04 _(7.84)
	Widowed	00 ₍₀₎	00 ₍₀₎	04 _(7.84)	10 _(19.61)	07 _(13.73)
	Total	02 _(3.92)	03 _(5.88)	13 _(25.49)	33 _(64.71)	35 _(68.63)
Distance	0-20 km	00 ₍₀₎	02 _(3.92)	05 _(9.80)	19 _(37.25)	18 _(35.19)
	21-50 km	00 ₍₀₎	00 ₍₀₎	01 _(1.96)	05 _(9.80)	05 _(9.80)
	51- 100 km	00 ₍₀₎	01 _(1.96)	03 _(5.88)	02 _(3.92)	04 _(7.84)
	Beyond 100 km	02 _(3.92)	00 ₍₀₎	04 _(7.84)	07 _(13.73)	08 _(15.69)
	Total	02 _(3.92)	03 _(5.88)	13 _(25.49)	33 _(64.71)	35 _(68.63)
Alcohol	Yes	00 ₍₀₎	01 _(1.96)	04 _(7.84)	18 _(35.29)	23 _(45.10)
	No	02 _(3.92)	03 _(5.88)	08 _(15.69)	15 _(29.41)	12 _(23.53)
	Total	02 _(3.92)	04 _(7.84)	12 _(23.53)	33 _(64.71)	35 _(68.63)
Reason for LFU	Psychiatric problem	00 ₍₀₎	00 ₍₀₎	00 ₍₀₎	03 _(5.88)	02 _(3.92)
	Family disturbances	00 ₍₀₎	00 ₍₀₎	01 _(1.96)	05 _(9.80)	06 _(11.76)
	Death in family	00 ₍₀₎	00 ₍₀₎	02 _(3.92)	06 _(11.76)	02 _(3.92)
	Illness	00 ₍₀₎	00 ₍₀₎	01 _(1.96)	00 ₍₀₎	00 ₍₀₎
	Other treatment	00 ₍₀₎	00 ₍₀₎	01 _(1.96)	04 _(7.84)	05 _(9.80)
	Adverse drug effect	01 _(1.96)	02 _(3.92)	01 _(1.96)	02 _(3.92)	05 _(9.80)
	Migration	00 ₍₀₎	01 _(1.96)	03 _(5.88)	09 _(17.65)	09 _(17.65)
	Others	01 _(1.96)	00 ₍₀₎	04 _(7.84)	04 _(7.84)	06 _(11.76)
	Total	02 _(3.92)	03 _(5.88)	13 _(25.49)	33 _(64.71)	35 _(68.63)

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Psychiatric problem	00 ₍₀₎	00 ₍₀₎	00 ₍₀₎	03 _(5.88)	02 _(3.92)
Family disturbances	00 ₍₀₎	00 ₍₀₎	01 _(1.96)	05 _(9.80)	06 _(11.76)

Table 1. Patient Characteristics and Socio-Demographic Features of Lost To Follow Up Cases No. (%)

		Male	Female	TOTAL
Duration of ART				
	0-1 month	7 (13.73)	2 (3.92)	9 (17.65)
	1-3 months	8 (15.69)	6 (11.76)	14 (27.45)
	4-6 months	5 (9.8)	3 (5.88)	8 (15.69)
	7-12 months	4 (7.84)	2 (3.92)	6 (11.76)
	More than 1 year	11 (21.57)	3 (5.88)	14 (27.45)
Condition of patient at restart				
	Weakness	12 (23.53)	5 (9.80)	17 (33.33)
	Asymptomatic	12 (23.53)	8 (15.69)	20 (39.22)
	Tuberculosis	8 (15.69)	2 (3.92)	10 (19.61)
	Oral infection	1 (1.96)	0 (0)	1 (1.96)
	Diarrhea	1 (1.96)	1 (1.96)	2 (3.92)
	In-patient	1 (1.96)	0 (0)	1 (1.96)
Why they Restarted?				
	Weakness	7(13.73)	1(1.96)	8(15.69)
	Family dispute resolved	3(5.88)	1(1.96)	4(7.84)
	Return back home	6(11.76)	4(7.84)	10(19.61)
	No response to Alternative treatment	4(7.84)	0(0)	4(7.84)
	Return after family member's death	1(1.96)	5(9.80)	6(11.76)
	Opportunistic infection	5(9.80)	1(1.96)	6(11.76)
	Phone call from ART Centre	3(5.88)	1(1.96)	4(7.84)
	Home visit by ORW	2(3.92)	0(0)	2(3.92)
	Doctor's advice	2(3.92)	1(1.96)	3(5.88)
	Others	2(3.92)	2(3.92)	4(7.84)

Table 2

DISCUSSION: We collected data of fifty one HIV sero-positive patients who were started on ART, who subsequently lost to follow-up and who restarted ART between January 2012 and September 2012. Male LFUs significantly out-numbered females by a double¹. This could probably be explained by the fact that males were from working class and so had an easy access to the ART center as compared to females who were predominantly housewives had limited access to the services provided by the ART center.

Non-adherence was high in patients more than 35 years of age and least in teenagers.²The majority of patients belonging to age group more than 35 years was from a working class and had

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migrated for work reasons came back to their original place of work and hence restarted the ART. Drivers and manual laborers were a sizeable number of LFUs. Both these groups were migratory population and gave history of frequent change of workplace and they could take ART medications only when they returned home. Illiteracy contributed to a significant no. of LFU and a greater proportion of these were females.³

Majority of the patients belonged to a low income class (earning below Rs.5000/month). These patients, who were on daily wages, preferred to remain absent on scheduled visit to the ART center. As far as the distance from the ART center is concerned, most of them lived within 20 kilometer area and only 25% patients lived beyond 100 kilometers⁴. There were 24 (47.06%) patients who were married and out of these 12 male patients were discordant, while only one female was discordant. The spouses of these patients being not HIV infected, the compliance was seriously affected and their turn-out to the ART center was less as compared to those couples in which both the spouses were HIV infected.

The reasons why our patients who were LFU are of great importance as they are different for every center and knowing these will help us to modify our policies to prevent more LFUs.^{5,6} In this study, migration was the most common reason as about 25.6 % patients who restarted ART were from labour class and had frequent change of place either within the state or outside the state. The next common cause was death of a family member. This factor was important in females as they could not attend the center on the day scheduled.

Family disturbances like stress, marital disharmony and illness related depression were seen only in the males and more so in discordant couples^{7,8}.

Drug related adverse effects caused about 11.76% patients to discontinue ART and in other studies this was one of the most common reasons for LFU. Alternative treatment like Ayurvedic, Homeopathic, Unani, naturopathy and similar modalities were resorted to by about 9.80% patients. Once there was no response to these forms of treatment or there was deterioration in the physical health, these patients came back to the ART center for restarting ART⁹.

The condition of the patient while restarting the treatment was assessed and we found that most had generalized weakness (33.3%) and 19.6% patients had some or the other opportunistic infection.¹⁰ More than 50% of the patients had worsening of their disease. Alcoholism was observed in 45% of patients, exclusively in males and majority was above 35 years of age⁸. The duration of LFU from initiation of treatment was either less than 3 months or more than a year. This shows that the first three months of initiation of ART are crucial in maintaining good adherence¹².

When we questioned about the reason why they came back to the ART center, maximum number of patients stated that they had come to Pune for work and so had enrolled themselves here. After going to the native place, these patients did not transfer out and had no medicines during that period. They returned back to Pune for various reasons. The next common reason for restarting ART was generalized weakness and debility and this group of patients believed that their symptoms would resolve after restarting ART. Similar number of patients restarted due to opportunistic infections.¹³

All the LFU patients were contacted by telephone by the counselors, but communication was established only with 30% of the patients. Out of these, only 7.8 % responded positively and were able to start ART again. Thus, many patients could not be traced due to incorrect phone numbers and

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address given by them. We therefore need to improve upon the data recording and patient tracking system.¹⁴

Conclusion:

Our study brings to light the various reasons for non-compliance and non-adherence to ART. Migration being a very important issue, special care needs to be taken in maintaining records of these patients. Alcoholism remains an important social stigma and further aggravates non-adherence. Motivation for alcohol abstinence and prompt referral to de-addiction center is essential. Incidence of being lost to follow-up is high in discordant couples. Generalized weakness, opportunistic infections and return to the native place were the eminent features noted in patients who returned back to restart antiretroviral therapy.

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